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Cohort Profile: A Data Linkage Cohort to Examine Health Service Profiles of People with Intellectual Disability in New South Wales, Australia

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ABSTRACT

Purpose: People with intellectual disability are a minority group who experience poorer physical and mental health than the general population and difficulty accessing healthcare services. There is lack of knowledge about the healthcare service needs and gaps experienced by people with intellectual disability. This study aims to interrogate a large linked administrative dataset to provide evidence to inform the development of improved health and mental health services for this population.

Participants: A retrospective cohort of people with intellectual disability (n= 51,452) from New South Wales (NSW), Australia to explore health and mental health profiles, mortality, pattern of health service use, and associated costs between 2005-2013. The datasets include: the Disability Services Minimum Data Set; Admitted Patients Data Collection; Emergency Department Data Collection, Australian Bureau of Statistics Death Registry and Registry of Births, Deaths and Marriages. Mental health service utilisation will be compared to a cohort of people who used mental health services regardless of their intellectual disability status (n=1,073,139) and service utilisation other than for mental health will be compared with published data from the general population.

Findings to Date: The median age of the cohort was 24 at the time of the last hospital admission and 21 at the last emergency department presentation. The cohort has a higher proportion of males than females and accounts for 0.6% of the NSW population in 2011. Over 70% had up to five emergency department presentations and hospitalisations between 2005-2012. A high proportion of people with intellectual disability live in the most disadvantaged neighbourhoods.

Future Plans: Results from the data linkage will be used to inform the development of more responsive healthcare, including improved interactions between health, social and disability supports. In a wider context, the results will also assist the development of more inclusive policy frameworks for people with intellectual disability.

Keywords: *data linkage, mental health, service utilisation, intellectual disability, disability services, health services*

Strengths and Limitations

- This data linkage study builds a rich resource which allows the in depth examination of the health profile and service contact of people with intellectual disability.
- In the Australian context of dispersed and relatively low population size, this is the most efficient methodology, yet in itself requires considerable time and financial resources.
- Results will be used to inform the development of more appropriate service models and policy frameworks for people with intellectual disability.
- Our study includes only people with intellectual disability who have received disability services for intellectual disability or who have been diagnosed or identified by the hospital or emergency department as having an intellectual disability.
- Administrative data are not collected specifically for research but rather for record keeping and aggregate data purposes; therefore, some variables of potential interest are not available.

INTRODUCTION

People with intellectual disability are a minority group, accounting for approximately 1% of the population[1]. Also known as Intellectual Developmental Disorder, Intellectual disability, is an enduring condition involving impairment of general mental abilities which is first apparent during the developmental period and impacts significantly on the person's adaptive functioning[2]. Typically, a person with intellectual disability has an extremely low IQ score (measured as two or more standard deviations below the population mean) with deficits in adaptive behaviours and a reduced capacity to engage in conceptual cognitive functions such as learning, reasoning and planning[2]. Compared to the general population, people with intellectual disability are more likely to experience poor physical and mental health including complex health conditions such as epilepsy, sensory impairments, gastro-intestinal problems, respiratory disorders, obesity, diabetes, osteoporosis and oral health problems[3]. A lower life expectancy than the general population underscores the significant health inequality experienced by this population group[4].

The prevalence of mental disorders is very high, with recent estimates in children and adolescents with intellectual disabilities indicating comorbidity rates of between 30 and 50%[5]. Compared to the general population, people with intellectual disability experience higher rates of schizophrenia, affective disorders, anxiety disorders and dementia, and rates of mental disorders in this population increase in keeping with the degree of disability[6-8]. Schizophrenia has an earlier onset in people with intellectual disability, underscoring a specific developmental vulnerability to mental illness, and the importance of timely access to psychiatric services for this group[9].

Despite the over-representation of physical and mental disorders, access to health and mental health services for people with intellectual disability in Australia is limited and falls far short

of that for the general population[10, 11]. Barriers to effective health and mental health care for people with intellectual disability include: a lack of substantial epidemiological data on prevalence of physical and mental illness in people with intellectual disability; poor identification of people with intellectual disability due to masking and comorbidity[9]; unavailability or lack of appropriate application of existing assessment instruments; discrimination in healthcare systems[12]; a dearth of data on the interaction between, and distinct roles and responsibilities of, disability and mental health services[13]; a lack of training and confidence of health professionals in treating people with intellectual disability[14-17]; poor understanding by carers[18], disability and mental health workers of the manifestations of mental disorders in people with an intellectual disability[19, 20]; a lack of coherent service models; inadequate funding for intellectual disability mental health services[13]; poor coordination between services and treating agencies[21]; scant services preventing involvement in the criminal justice system[22] and a lack of specific inclusion of people with intellectual disability in the formulation of health and mental health policy.

Here we describe the creation of a linked administrative dataset resource from which we describe the health and mental health profile and service use of people with intellectual disability. Potential analyses include descriptive profiling of the diagnoses given to people with intellectual disability within health service systems, characteristics and predictors of service use and costs, examination of health outcomes and their predictors. Comparisons can be made with the general population, as derived from both the linked dataset and publically available statistics. Although the main objective of the overall program of work is to build a detailed profile of the health and health service system use of people with intellectual disability, the substantial unmet mental health needs of people with intellectual disability[13, 23] and award of specific funding have created an imperative for a specific mental health subtheme.

The data linkage which forms the basis for this work has been made possible through a National Health and Medical Research Council Australia funded Partnerships for Better Health grant (ID: APP1056128; Title: Improving the Mental Health Outcomes of People with an Intellectual Disability), which is a larger collaborative project including academics, government and non-government organisations and people with intellectual disability. The broader Partnership work has several themes including Big Data, qualitative work examining barriers and enablers to access, and a national and state policy analysis. A cohesive knowledge translation framework has been developed which triangulates results from each theme and uses the findings to guide the development of healthcare services and policy for people with intellectual disability and mental illness at both an Australian Government and State Government level. The data linkage component has several benefits including large sample sizes and the potential for greater efficiency in time and resources of longitudinal data. Interrogation of linked data identifies the linkages and gaps between service sectors, and the benefit of cross-sector work.

COHORT DESCRIPTION

Administrative datasets relating to disability services, health services and mortality in NSW, Australia, have been linked at an individual level to allow an examination of the pattern and determinants of service use/contact over time both for those with established intellectual disability and those without known intellectual disability.

Project Resourcing and Development

Considerable time and resources have been required to develop the data linkage component of the study. Piloting of the project occurred in 2012, when the team sought approval to link a

subset of one-third of the NSW ambulatory mental health dataset to the Disability Services Minimum Dataset (DS-MDS). Following proof of concept and publication of initial results[24] further funding was obtained to undertake the current linkage. Overall resourcing to date has been substantial and includes approximately 2 years full-time salary equivalents for a research officer, 2 year full-time salary equivalent for a data analyst, oversight of the project by a senior academic, substantial costs associated with linkage and storage of datasets, and multiple in kind contributions from partner agencies and collaborators.

Overview of data sources

There is no single registry which collects information about people with intellectual disability. In this project, multiple datasets have been utilised to help identify those with intellectual disability. All people identified as having intellectual disability fulfilled either Diagnostic and Statistical Manual of Mental Disorders (DSM) IV or International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10) criteria for a diagnosis of intellectual disability.

Disability services data

The Disability Services Minimum Dataset (DS-MDS) is a de-identified dataset which collates information about people receiving disability services in NSW, including the nature of their disability and the services provided to persons with a disability. The main services provided by the agency, Ageing, Disability and Home Care (ADHC), include accommodation, community support, community access and respite. Such information is routinely collected by each Australian State and Territory under the National Disability Agreement[25]. Given the services provided, the DS-MDS contains information on service recipients' demographics, living arrangements, support needs, carers and services received. A full list of the variables in this dataset is presented in Supplementary file 1. From the NSW DS-MDS, a

cohort of people with intellectual disability who resided in NSW and who were registered to receive a disability service between 01 July 2005 and 30 June 2012 was identified. Fulfilment of DSM IV criteria for intellectual disability was required in order to be eligible to receive a service due to intellectual disability.

Health Services Data

1. NSW Admitted Patient Data Collection

The NSW Admitted Patient Data Collection (APDC) is a de-identified dataset which collates information on all admitted patient services provided by NSW public hospitals, public psychiatric hospitals, public multi-purpose services, private hospitals, and private day procedures centres. It contains dates of admissions and separations for each episode of care, up to 50 diagnoses relevant to each episode of care, the source of referral, separation mode and procedures based on ICD-10 Australian version[26]. The current project includes APDC data on separations that occurred between 1 January 2005 and 30 June 2012. A list of the variables in this dataset is included in Supplementary file 2.

2. NSW Emergency Department Data Collection

The NSW Emergency Department Data Collection (EDDC) is a de-identified dataset which collates information on presentations to an emergency department in a NSW public hospital. It includes dates and times of presentation and discharge, reason for presentation, triage category and outcome of the presentation (discharge, transfer or death). The study includes data from 1 January 2005 to 30 June 2012. There are 150 ED centres in NSW and 90 (60%) of those participated in the data collection[27]. Although only 60% of the ED centres participated in the data collection, these reporting centres are the larger centres hence a

substantial proportion of the presenting population is covered. A listing of variables in the EDDC is displayed in Supplementary file 3.

Mortality Data

There are two datasets containing mortality information. Observations in both datasets are based on year of the registration of the death rather than the year the death occurred, although in most cases these are equivalent. The mortality information available for linkage includes only people who died in NSW.

1. NSW Registry of Births, Deaths and Marriages Data

The NSW Registry of Births, Deaths and Marriages (RBDM) registers all deaths that occur in NSW and contains death certificate raw and uncoded data. Data is available from January 2005 to June 2013. A listing of variables in the RBDM is displayed in Supplementary file 4.

2. Australian Bureau of Statistics Deaths Registration Data

The Australian Bureau of Statistics (ABS) Deaths Registration Data contains ICD-10 International version coded causes of death information and date of death. For our project, ICD-10 coded causes of deaths were available until 2007. A list of variables is included in Supplementary file 4. Data are available from January 2005 to December 2007.

Cohort definition

Our data linkage contains the records of a cohort of people with intellectual disability who have ever received disability services in NSW recorded in the DS-MDS described above and those who have been identified as having intellectual disability through diagnosis codes in the APDC and the EDDC in a NSW hospital. These “intellectual disability” codes are: F700-F701; F708-F709; F710-F711; F718-F719; F720-F721; F728-F729; F730-F731; F728-F729;

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3 F730- F731; F738-F739; F780-F781; F788-F791; F843-F844; F798-F799; Q900-Q902;
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5 Q909; Q910-Q912; Q913; Q914-Q916; Q917; Q930-Q939; Q992; P043; Q860; Q861; Q862;
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7 Q868 Q870-Q873; Q875; Q878; Q898. These codes include intellectual disability due to
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9 childhood disintegrative and overactive disorders associated with mental retardation,
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11 intellectual development delay, mild through profound mental retardation, Down syndrome
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13 and other chromosomal anomalies associated with mental retardation, Fragile X syndrome
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15 and congenital malformation syndromes due to known exogenous causes. Those diagnosed
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17 with autism without a co-occurring intellectual disability are not defined as having an
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19 intellectual disability for the purposes of this project. The intellectual disability cohort
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21 accounts for 0.6% of the NSW population in 2011 and people with mild intellectual disability
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23 may be underrepresented.
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28 To compare mental health profile and service utilisation in people with and without
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30 intellectual disability, an overarching cohort comprising people who either used mental health
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32 services or who had a mental health diagnosis, regardless of the intellectual disability status,
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34 was also formed (n=1,073,139). People in this cohort had at least one admission to a
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36 psychiatric ward or were diagnosed with at least one mental health ICD10 code (F00-F25,
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38 F28-F48, F50, F51, F53-F73, F78-F91, F93-F99) during any hospital admission (psychiatric
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40 or non-psychiatric) or during any presentation to an emergency department. We then link this
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42 data to the intellectual disability status in order to quantify and compare rates and patterns of
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44 mental ill health in people with intellectual disability and the general population.
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49 For other health utilisation, we will compare the results of our cohort with information
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51 published by HealthStats NSW or the Australian Institute for Health and Welfare (AIHW).
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53 We will calculate rates of ED presentations, non-mental health hospital episodes and death in
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55 our cohort using appropriate datasets. For comparison with the general population, we will
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57 use AIHW published results for ED presentations in NSW and all cause hospitalisations in
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NSW as well as death from HealthStats NSW. To make direct comparisons between the cohort of people with intellectual disability and the general population, we will standardise the utilisation rates on age and sex using the Australian Standard Population.

Data Linkage

Linkage of the aforementioned datasets was performed by the NSW Centre for Health Record Linkage (CHeReL). The CHeReL maintains a linkage system for health-related data in NSW in accordance with all ethical, legal privacy and confidentiality requirements. The CHeReL keeps a Master Linkage Key (MLK) that consists of continuously updated links between most NSW Health datasets. The CheReL does not house the data; all datasets are kept by the respective data custodians.

Individuals in the DS-MDS were identified and their records matched in a deterministic manner using a Statistical Linkage Key (SLK581) identifier. Records in the APDC, EDDC, and RBDM are matched to individuals using an MLK[28]. The CHeReL created an SLK581 identifier for the matched APDC, EDDC, and RBDM records and linked this with the SLK581 keys in the DS-MDS. We do not have information on the false positive rate using the deterministic approach; however it is expected to be higher than 5/1000 aimed for by the CHeReL. Currently, the CHeReL linked 43,772 (59%) records of people in DS-MDS to APDC, EDDC, ABS or RBDM and 29,902 (41%) records did not link to APDC, EDDC, ABS or RBDM.

Data custodians provided the CHeReL with an encrypted client number and relevant personal information for all clients over the relevant time periods. The CHeReL linked the DS-MDS database to the NSW data collections of APDC, EDDC, ABS and RBDM using the linkage method described above, and provided each data custodian a project person number (PPN) and an encrypted client number for each database. The data custodians decrypted the source

record number and merged the PPN with their datasets for use in this project. The source record number was removed and the researchers were provided with de-identified files containing only the PPN and relevant study variables. The PPN allowed for merging the various datasets as needed.

Data cleaning and plan of analyses

Once the linked data was received, a data cleaning process was carried out including checking for unexpected trends, checking that the data was complete with all requested variables available and a validity check. People who appeared with a different sex or different data of birth/date of death in different datasets were excluded from the dataset.

The analyses described in this paper include the demographic profiles including age, sex, area of residence and socioeconomic status as well as health resource utilisation for people with intellectual disability.

Ethics

Ethics approval was obtained from the NSW Population and Health Services Research Ethics Committee (AU RED Study Reference Number: HREC/13/CIPHS/7; CINSW Reference Number: 2013/02/446) and access to the data sets was granted by relevant data custodians. The timeframe from submitting the ethics application to ethics approval was approximately 12 months and another 8 months from ethics approval to receipt of the data.

FINDINGS TO DATE

Percentages of people with intellectual disability in each individual dataset are 57% in the DS-MDS; 11% in the EDDC and 3% in the APDC dataset. A total of 34% appear in all three datasets, 6% appear only in the DS-MDS and the APDC, 10% appear in both the DS-MDS and the EDDC and 4% appear in both the EDDC and the APDC. Note that in order to be

included in our cohort, an individual had to receive a service with an intellectual disability flag. However, not all people with intellectual disability would necessarily also have a hospital admission or ED presentation record. Overall, 82% of the cohort received disability services due to their intellectual disability. Of the remaining 18% who did not receive disability services due to intellectual disability, 2.3% received disability services for non-intellectual disability related needs.

Figure 1

Table 1 displays the demographics of the study population in each dataset APDC, EDDC and RBDM. The data shown is on a person level, and a person may have multiple records in the full analysis period of 2005 to 2012. Our cohort comprises 51,452 people with intellectual disability with a median age of 24 at the time of their last admission to a hospital or day procedure centre and a median age of 21 at their last presentation to an emergency department. The median age of death is 56 years. The cohort has a higher proportion of males than females: across the datasets, the proportions of males range between 57 and 60%. Two-thirds of people live in a major city and about one-quarter lives in an inner regional city and 6% live in outer regional cities. Across all health services, only 15% of people with intellectual disability live in the least disadvantaged neighbourhoods.

Table 2 presents information from the APDC and EDDC datasets on a record level (i.e. multiple records for one person). As the RBDM is the same whether it is presented at a person (Table 1) or record level, it has not been retabulated in Table 2.

Proportions of intellectual disability are similar on a record level and on a person level basis. Percentages of the records in the APDC and in EDDC that were defined as from people with intellectual disability are 3% and 12%, respectively. Consistent across all datasets a higher proportion of males with intellectual disability receive health services than females (Tables 1 & 2).

Table 1: Health service and mortality profiles as recorded in the dataset person level (at the last record), numbers presented in n (%) unless otherwise specified

	APDC	EDDC	Mortality (RBDM)
Number of people (% of sample)	28,233 (2.7)	24,242 (10.9)	2844 (1.2)
Median (IQR) age at the last event, years	24 (10 – 46)	21 (10 – 41)	56 (35 – 68)
0-4	3408 (12.1)	2115 (8.7)	160 (5.6)
5-14	5878 (20.8)	6197 (25.6)	149 (5.2)
15-24	4955 (17.6)	5202 (21.5)	194 (6.8)
25-34	3279 (11.6)	3048 (12.6)	181 (6.4)
35-44	3210 (11.4)	2618 (10.8)	246 (8.7)
45-54	2993 (10.6)	2361 (9.7)	424 (14.9)
55-64	2466 (8.7)	1768 (7.3)	556 (19.6)
65-74	1306 (4.6)	688 (2.8)	494 (17.4)
75-84	580 (2.1)	203 (0.8)	323 (11.4)
85 and over	158 (0.6)	42 (0.2)	117 (4.1)
Invalid data	0	0	0
Sex			
Female	11,753 (41.6)	9529 (39.3)	1214 (42.7)
Male	16,480 (58.4)	14,712 (60.7)	1629 (57.3)
Other	0	1 (0.0)	1 (0.0)
Ever received disability services	20,199 (71.5)	22,304 (92.0)	1448 (50.9)
Remoteness Area of residence			
Major Cities	19,042 (67.5)	16,215 (66.9)	1993 (70.1)
Inner regional	7017 (24.9)	6524 (26.9)	639 (22.5)
Outer regional	1791 (6.3)	1295 (5.3)	183 (6.4)
Remote	137 (0.5)	85 (0.4)	9 (0.3)
Very remote	7 (0.0)	8 (0.0)	1 (0.0)
Unknown	239 (0.9)	115 (0.5)	19 (0.7)
Index of Relative Socioeconomic Disadvantage in NSW of residence			
1 st quintile (most disadvantaged)	5633 (20.0)	4864 (20.1)	533 (18.7)
2 nd quintile	5563 (19.7)	4853 (20.0)	588 (20.7)
3 rd quintile	7314 (25.9)	6569 (27.1)	736 (25.9)
4 th quintile	5523 (19.6)	4655 (19.2)	560 (19.7)
5 th quintile (least disadvantaged)	3965 (14.0)	3190 (13.2)	408 (14.4)
Unknown	235 (0.8)	111 (0.5)	19 (0.7)

The demographics presented in the table are from the last admission or use of ED within the analysis period in each dataset.

The proportion of people who received disability services is lower when assessed at the record level (59% and 78%) than on the person level (72% and 92%), in both the APDC and EDDC datasets. This indicates that those who have ever received disability services have, on average, fewer ED presentations and admissions to hospital than those who have not received disability services.

Overall, for the APDC and EDDC, there are on average 8 records per person in the full record database. The number of hospitalisations (data from the APDC) is displayed in Figure 2 and the number of ED presentations (data from the EDDC) is displayed in Figure 3. The distribution of the number of hospitalisations (APDC) and ED presentations (EDDC) is highly skewed.

Table 2: Health service profiles as recorded in the dataset (record level), numbers presented in n (%) unless otherwise specified

	APDC	EDDC
Total records (% of sample)	225,904 (2.9)	200,868 (11.6)
Date ranges	1 Jan 2005 – 30 Jun 2012	1 Jan 2005 – 30 Jun 2012
Median (IQR) age at the event, years	29 (11-49)	26 (13 – 42)
0-4	31,889 (14.1)	23,545 (11.7)
5-14	35,322 (15.6)	30,448 (15.2)
15-24	32,967 (14.6)	40,385 (20.1)
25-34	25,602 (11.3)	32,820 (16.3)
35-44	30,241 (13.4)	31,910 (15.9)
45-54	29,269 (13.0)	22,823 (11.4)
55-64	20,473 (9.1)	13,578 (6.8)
65-74	11,991 (5.3)	4041 (2.0)
75-84	711 (3.2)	1100 (0.6)
85 and over	1038 (0.5)	213 90.1)
Invalid data	1 (0.0)	5 (0.0)
Sex		

	APDC	EDDC
Female	100,387 (44.4)	87,930 (43.8)
Male	125,515 (55.6)	112,927 (56.2)
Other/missing	2 (0.0)	11 (0.0)
Ever received disability services	133,437 (59.1)	156,038 (77.7)
Remoteness Area of residence		
Major Cities	161,762 (71.9)	133,770 (66.6)
Inner regional	45,433 (21.1)	52,436 (26.1)
Outer regional	13,897 (5.8)	11,343 (5.7)
Remote	2,147 (0.6)	372 (0.2)
Very remote	61 (0.0)	38 (0.0)
Unknown	2,604 (0.7)	2909 (1.5)
Index of Relative Socioeconomic Disadvantage in NSW of residence		
1 st quintile (most disadvantaged)	47,338 (21.0)	44,672 (22.2)
2 nd quintile	42,141 (18.7)	40,735 (20.3)
3 rd quintile	55,231 (24.5)	53,752 (26.8)
4 th quintile	45,153 (20.0)	38,005 (18.9)
5 th quintile (least disadvantaged)	33,455 (14.8)	20,818 (10.4)
Unknown	2,586 (1.4)	2886 (1.4)

As seen in Figure 2 and 3, over 70% of people with intellectual disability have up to 5 ED presentations and hospitalisations.

Figure 2

Figure 3

Future Directions

Four major themes will be the focus of the project: hospital admissions, ED presentations, mortality and costs. Analyses will include predictors of hospital admission and re-admission, frequency and length of stay for health and mental health admissions. We will investigate the demographics of people with intellectual disability who present at the Emergency Department, their rate of service use, arrival mode and whether ED presentations were considered a GP-type presentation. Mortality rates and predictors of mortality in people with

intellectual disability will be examined as well as associations between use of disability services and comorbidities on mortality. Finally, costs of hospital services will be investigated.

STRENGTHS AND LIMITATIONS

Our linkage approach enables the inclusion of a broad range of people with intellectual disability in NSW, the most populous state in Australia. Similarities in demography between most states and territories in Australia enhances the generalisability of our results to Australian service users with an intellectual disability.

The data linkage enables us to conduct analyses examining patterns of service use related to different components of the health service system (inpatient, emergency, adult services, children and younger people’s services), and costs associated with health care, and mortality, cause and predictors of death. A greater understanding of service and indices of health system efficiency for people with intellectual disability will emerge, e.g. through the frequency and timeframe of readmissions to hospital, representations to ED and their predictors. The inclusion of an additional mental health cohort in our dataset will allow a direct comparison between the mental health profile and service use of people with and without intellectual disability.

The analysis of linked health and disability service data fills a current gap in the Australian knowledge base regarding the health profile and service system needs of intellectual disability. These data will be triangulated with the other two main projects within this program of research, to improve access to and quality of healthcare for people with intellectual disability.

Our results will inform sector and services development. In light of the Australian rollout of the National Disability Insurance Scheme (NDIS) including in NSW, the project is an important source for informing policy and practices to improve the coordination between health and disability sectors. Our study will establish baseline health and mental health profiles, service use and costs across multiple components of the health services system, against which NDIS-related change can be interrogated.

A number of challenges have been encountered in establishing this data infrastructure. The data linkage process is time- and resource -intensive. Researchers need to be aware that the process of applying for, combining and cleaning these dataset can take months-years and requires experienced data analysts. In particular the relatively lengthy process of applying for/waiting for the linked data and receiving ethics clearance can be a major challenge for research projects that are only funded from external sources for a limited amount of time. As with most administrative datasets, data has been collected for administrative rather than clinical purposes, and as such has significant shortcomings. Coverage is limited in three respects. Our data does not reflect all emergency department presentations because not all departments contribute to this minimum dataset. Importantly however, the majority of people live in areas with contributing emergency departments, so the impact is minimal in our study. We cannot identify all people with intellectual disability, rather those who have received disability services for intellectual disability or who have been diagnosed or identified by the hospital or emergency department as having an intellectual disability. Therefore, we are missing those individuals with intellectual disability who were not considered eligible for disability services and in whom intellectual disability was not recognised or coded by health services. The excluded individuals are highly unlikely to be a random subset of those with intellectual disability; rather they are more likely to be people with milder intellectual disability and/or with additional disadvantage which limits access to services. Additional

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linkage to other datasets with intellectual disability identifiers would overcome this problem to some extent. Further, with the exception of the ability for direct comparison within mental health services, we do not have person level data of the general NSW population and hence need to compare other data-points to publically available data sources.

Record linkage can sometimes erroneously make false-positive links or fail to link when a true link exists (false negative). Additionally, administrative data are not collected specifically for research but rather for record keeping and aggregate data purposes. Some variables, for example, relating to severity of disability or measures of adaptive behaviour, that we would like to include in our models are not available in the data. In turn, this may increase the chances of omitted variable bias in our models. The current linkage does not include community health services or general practitioner records which may add additional value to the analyses as it requires linking data from different jurisdiction and not feasible at the time of this study. Finally, our cohort with intellectual disability is heterogeneous as we used multiple data sources with differences in definition or context of diagnosis of intellectual disability, which can be easily adjusted in the analyses.

An update of the cohort with inclusion of additional data is currently in progress. Specifically, we will add data from Corrective Services NSW, NSW Department of Education and NSW Public Guardian and we will extend the timeframe to 2001-2016. This will allow us to identify, quantify and cost health and other services provision to people with ID within the various cohorts of interest.

In conclusion by interrogating the linked disability and health datasets and triangulating this with data derived from an analysis of Commonwealth and State Mental Health Policy and a qualitative research approach with stakeholder engagement to improve accessibility, this

project will inform the development of more appropriate service models and policy frameworks for people with intellectual disability.

COLLABORATION

Initial data analyses and publications will be generated by investigators on the NHMRC partnerships for better health: Improving the mental health outcomes for people with an intellectual disability. However, the research team is open to potential research collaborations; researchers interested in collaboration should contact the corresponding author with their expression of interest. Access to the data and analytical files is only permitted with the expressed permission of the approving human research ethics committees and data custodians. Analysis of linked data is currently authorised to occur at only one location, owing to ethical considerations.

Funding The study is part of a National Health and Medical Research Council Australia funded Partnerships for Better Health grant (ID: APP1056128; Title: Improving the Mental Health Outcomes of People with an Intellectual Disability).

Ethics approval Ethics approval was obtained from the NSW Population and Health Services Research Ethics Committee (AU RED Study Reference Number: HREC/13/CIPHS/7; CINSW Reference Number: 2013/02/446) and access to the data sets was granted by relevant data custodians.

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Project Staff and Students: Angela Dew, Preeyaporn Srasuebkul, Erin Whittle, Simone Reppermund, Snow Lee, Bronwyn Newman, Tess Heintze

Partner Organisations: Agency for Clinical Innovation – Intellectual Disability Network, NSW Department of Family & Community Services - Ageing, Disability and Home Care, NSW Department of Education, NSW Department of Justice - Corrective Services NSW, NSW Ministry of Health – Justice Health & Forensic Mental Health Network, Mental Health Commission of NSW, NSW Ministry of Health – Mental Health & Drug & Alcohol Office, NSW Ministry of Health - InforMH, Mental Health Review Tribunal, National and NSW Council for Intellectual Disability, National Disability Services, NSW Office of the Public Guardian, NSW Ombudsman.

Data Sharing Direct access to the data and analytical files is not permitted without the expressed permission of the approving human research ethics committees and data custodians. Researchers interested in collaboration should contact the corresponding author with their expression of interest

Authors’ contributions JNT conceived and designed the study. KD, EE, DC, PS, EB, LD, TS, GS and TF participated in the conceptual design of the study. SR, PS, TH and JNT drafted the manuscript. PS and TH performed the analyses. TF provided statistical support. RR provided expertise about health economics. All authors critically revised the manuscript and contributed to interpretation of the data. All authors read and approved the final version of the manuscript.

Competing Interests None

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Figures

Figure 1: Number of people identified as having intellectual disability in DS-MDS, APDC and EDDC datasets

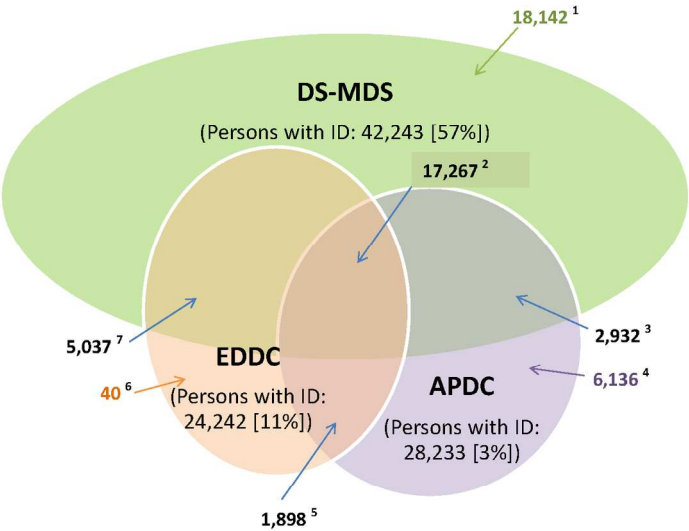
Figure 1 Legend:

- ¹ Persons with intellectual disability who have a record exclusively in the DS-MDS dataset
- ² Persons with intellectual disability who have records in the DS-MDS, APDC, and EDDC datasets
- ³ Persons with intellectual disability who have records in the DS-MDS and APDC datasets
- ⁴ Persons with intellectual disability who have a record exclusively in the APDC dataset
- ⁵ Persons with intellectual disability who have a record in the APDC and EDDC datasets
- ⁶ Persons with intellectual disability who have a record exclusively in the EDDC dataset
- ⁷ Persons with intellectual disability who have records in the DS-MDS and EDDC datasets

Figure 2: Distribution of the number of records per person by intellectual disability status for the APDC dataset

Figure 3: Distribution of the number of records per person by intellectual disability status for the EDDC dataset

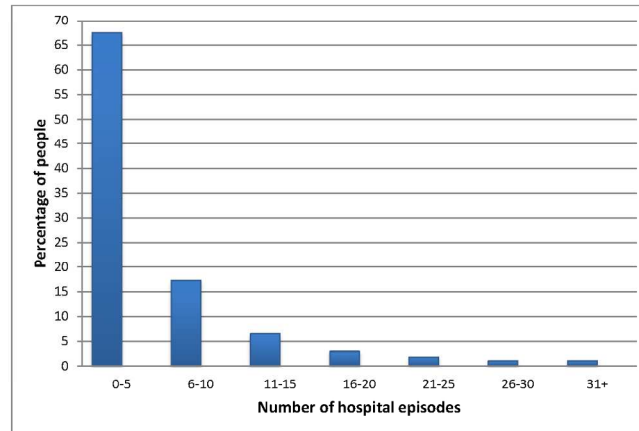
For peer review only



Number of people identified as having intellectual disability in DS-MDS, APDC and EDDC datasets†

Figure 1 Legend:† 1 Persons with intellectual disability who have a record exclusively in the DS-MDS dataset† 2 Persons with intellectual disability who have records in the DS-MDS, APDC, and EDDC datasets† 3 Persons with intellectual disability who have records in the DS-MDS and APDC datasets† 4 Persons with intellectual disability who have a record exclusively in the APDC dataset† 5 Persons with intellectual disability who have a record in the APDC and EDDC datasets† 6 Persons with intellectual disability who have a record exclusively in the EDDC dataset† 7 Persons with intellectual disability who have records in the DS-MDS and EDDC datasets†

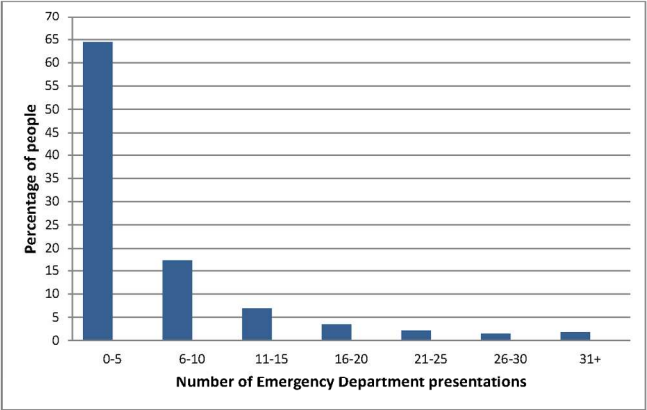
Figure 1
210x297mm (200 x 200 DPI)



Distribution of the number of records per person by intellectual disability status for the APDC dataset

Figure 2

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Distribution of the number of records per person by intellectual disability status for the EDDC dataset
Figure 3
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Table 1: List of variables in Disability Service Minimum Data Set (DS-MDS)

Variable Name	Description
Service user	
Birth date	The day, month and year when the person was born.
Birth date estimate flag	Whether or not the person's date of birth has been estimated.
Sex	The gender of the person.
Indigenous status	Whether or not a person identifies themselves as being of Aboriginal and/or Torres Strait Islander origin.
Country of birth	The country in which the person was born.
Interpreter required	Requirement for interpreter services as perceived by the person seeking assistance.
Communication method	The method of communication, including sign language, most effectively used by the person.
Living arrangements	Whether the person lives alone or with other related or unrelated persons.
Residential setting	The type of physical accommodation in which the person usually resides ('usually' being 4 or more days per week on average).
Primary disability group	<p>One of: Intellectual, developmental disability, autism, acquired brain injury, Learning Disability, Neurological, or Psychiatric.</p> <p>Disability groups are a broad categorisation of disabilities in terms of the underlying health condition, impairment, activity limitations, participation restrictions and environmental factors.</p> <p>Primary disability group is the disability group that most clearly expresses the experience of disability by a person. The primary disability group can also be considered as the disability group causing the most difficulty to the person (overall difficulty in daily life, not just within the context of the support offered by this service).</p>
Secondary disability or other significant disability group	<p>One of: Intellectual, Development Disability, Autism, Acquired Brain Injury, Learning Disability, Neurological, Psychiatric</p> <p>Disability group(s) (other than that indicated as being 'primary') that also clearly express the experience of disability by a person and/or cause difficulty for the person.</p>
Support needs – self-care	The need for personal help or supervision in the area of: a. Self-care—activities such as washing oneself, dressing, eating and/or toileting.
Support needs – mobility	The need for personal help or supervision in the area of: b. Mobility—moving around the home and/or moving around away from home (for instance, using public

Variable Name	Description
	transport), getting in or out of bed or a chair.
Support needs – communication	The need for personal help or supervision in the area of: c. Communication—making self understood by strangers/family/friends/staff, in own native language or most effective method of communication if applicable, and understanding others.
Support needs – interpersonal interactions and relationships	The need for personal help or supervision in the area of: d. Interpersonal interactions and relationships—including, for example, actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions.
Support needs – learning applying knowledge and general tasks and demands	The need for personal help or supervision in the area of: e. Learning, applying knowledge and general tasks and demands—understanding new ideas, remembering, solving problems, making decisions, paying attention, undertaking single or multiple tasks, carrying out daily routines.
Support needs – education	The need for personal help or supervision in the area of: f. Education—for example, the actions, behaviours and tasks an individual needs to perform at school, college or any educational setting.
Support needs – community (civic) and economic life	The need for personal help or supervision in the area of: g. Community (civic) and economic life—for example, participating in recreation and leisure, religion and spirituality, human rights, political life and citizenship, and economic life such as handling money.
Support needs – domestic life	The need for personal help or supervision in the area of: h. Domestic life—undertaking activities such as shopping, organising meals, cleaning, disposing of garbage, housekeeping, cooking and home maintenance. (This does not include care of household members, animals and/or plants).
Support needs – working	The need for personal help or supervision in the area of: i. Working—for example, undertaking the actions, behaviours and tasks needed to obtain and retain paid employment.
Carer – existence of	Whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person requiring support.
Carer – residency status	Whether or not a carer lives with the person for whom they provide care and support.
Carer – primary status	Whether the carer assists the person requiring support, in one or more of the following activities of daily living: self-care, mobility or communication.
Carer – relationship to service user	The relationship of the carer to the person for whom they care.
Carer – age group of carer	The age group of the carer.
Receipt of Carer Allowance	Receipt of the Carer Allowance (Child) by a parent or

Variable Name	Description
(child)	guardian of a person, if the service user is aged less than 16 years.
Labour force status	The self-reported status the person currently has in being either in the labour force (employed/unemployed) or not in the labour force.
Main source of income	The main source of income of the person, if they are aged 16 years or more.
Individual funding status	Whether service user is currently receiving individualised funding under the National Disability Act (NDA).
Services Received	
Funded Agency ID	ID code generated for the funded disability service provider or agency.
Service Type Outlet ID	ID code generated for the agency's service type outlet.
Service start	The date on which a person began to receive support from a Disability-funded outlet.
Date service last received	The date the person last received a service of this service type during the reporting period.
Service exit date	The date on which the person ceases to be a service user of the NDA-funded outlet.
Main reason for cessation of service	The reason that the person stopped receiving services from the outlet.
Service quantity – hours received (reference week)	The number of hours of support received by a person for this NDA service type in the 7-day reference week preceding the end of the reporting period.
Service quantity - Hours received (total)	The total number of hours of support received by a person for this service type (summed over the reporting period).
Service quantity - Hours received (total) – specific service	The total number of hours of support received by a person for this NDA service type (summed over the reporting period).
Service Type Outlet	
Service type	The support activity that the outlet has been funded to provide under the NDA.
Service type outlet postcode	Postcode of the location of the outlet.
Funding jurisdiction	The jurisdiction (state, territory or Australian Government) providing NDA funding to the Service Provider and the jurisdiction in which the funds are allocated.
Agency sector	The type of government or non-government sector to which the Service Provider (or outlet) belongs.
Number of service users	Total number of people receiving a particular funded service type under the NDA during the reporting period.
Total CSDTA funds	Total amount (recorded in whole dollars) of Disability funds provided to the outlet for the current reporting period.
Other source of funds	The types of funding sources which apply to your agency.

Table 2: List of variables in the APDC dataset

Variable
Hospital type (Public/Private)
Acute Hospital flag
Age
Area Health Service of facility
Local Health District of facility
Australian Refined Diagnosis Related Group
ARDRG version
Year and month
Clinical codeset
Condition onset flags
Cost weight A
Cost weight B
Cost weight C
Cost weight D
Cost weight E
Cost weight version
Country of birth (SACC)
Days in psychiatric unit
Diagnosis codes
DRG mode of separation
Emergency status
Emergency Department Status
Episode day stay length of stay in hours
Date
Episode end time
Episode leave days total
Episode length of stay
Episode of care type
Date
Episode start time
Facility type
Financial class
Financial program
Financial sub program
Health insurance on admit
Hours in ICU
Indigenous status
Involuntary days in psychiatric unit
Marital status
Major Diagnostic Category
Mode of separation
Patient postcode
Peer group
Procedure codes

Variable
Date
Recognised public hospital flag
Referred to on separation
Sex
Source of referral
Service Related Group
SRG version
State of residence
Unit type on admission
AHS 2005 CODE
LHD 2010 CODE
ML 2011 CODE
SA2 2011 CODE

Table 3: List of variables in the EDDC dataset

Variable
Actual departure date
Actual departure time
Age
Arrival Date
Arrival time
Birth date
Clinical codeset
Country of birth
Departure ready time
Principal ED diagnosis
Referral source
Type of visit
Facility
Area Health service of Facility
Local Health District of Facility
Facility type
Doctor seen date
Doctor seen time
Nurse Practitioner seen date
Nurse Practitioner seen time
Indigenous status**
Marital status
Mode of arrival
Mode of separation
Need for interpreter Service
Postcode of residence
Peer group
Recognised public hospital flag
Referred to on departure
Sex
State of usual residence
Triage category
Triage date
Triage time
AHS 2005 CODE
LHD 2010 CODE
SA2 2011 CODE

Table 4: List of variables in the RBDM and ABS datasets

Variable
Date of birth
Date of death
Age at death in years
Year of death registration
Local Health District (LHD) Code 2010 (of residence)
SA4 Geographic Region 2011 Code (of residence)
SA3 Geographic Region 2011 Code (of residence)
SA2 Geographic Region 2011 Code (of residence)
Underlying cause of death
Contributing cause of death

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	comments
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	Title page
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 5-7
Objectives	3	State specific objectives, including any prespecified hypotheses	Page 6-7
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 8-10
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Page 8-12
		(b) For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	A full list of all variables is listed in supplementary files 1-4. A summary of planned outcomes and future planned analyses is described on page 13-20
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 8-13
Bias	9	Describe any efforts to address potential sources of bias	Page 20
Study size	10	Explain how the study size was arrived at	Figure 1
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Only basic demographics are reported
		(b) Describe any methods used to examine subgroups and interactions	As above
		(c) Explain how missing data were addressed	As above
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Table 1 and 2
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1 and 2. Page 13-17
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	n/a
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Key results will be reported in research paper. This is a cohort profile paper with limited results. Basic results and demographics are presented in Tables 1 and 2
		(b) Report category boundaries when continuous variables were categorized	n/a
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	18	Summarise key results with reference to study objectives	Key results will be reported in research paper. This is a cohort profile paper with limited results.
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 19-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Key results will be reported in research paper. This is a cohort profile paper with limited results.
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 20
Other information			
Funding	22	Give the source of funding and the role of the	Page 21

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fund-ers for the present study and, if
applicable, for the original study on which the
present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

BMJ Open

Cohort Profile: A Data Linkage Cohort to Examine Health Service Profiles of People with Intellectual Disability in New South Wales, Australia

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Primary Subject Heading:	Mental health
Secondary Subject Heading:	Epidemiology, Health services research, Health economics
Keywords:	data linkage, MENTAL HEALTH, service utilisation, intellectual disability, disability services, health services

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Cohort Profile: A Data Linkage Cohort to Examine Health Service Profiles of People with Intellectual Disability in New South Wales, Australia

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ABSTRACT

Purpose: People with intellectual disability are a minority group who experience poorer physical and mental health than the general population and difficulty accessing healthcare services. There is lack of knowledge about healthcare service needs and gaps experienced by people with intellectual disability. This study aims to interrogate a large linked administrative dataset containing hospital admissions, presentations to emergency departments (ED) and mortality data to provide evidence to inform the development of improved health and mental health services for this population.

Participants: A retrospective cohort of people with intellectual disability (n=51,452) from New South Wales (NSW), Australia to explore health and mental health profiles, mortality, pattern of health service use, and associated costs between 2005-2013. The cohort is drawn from: the Disability Services Minimum Data Set; Admitted Patients Data Collection; Emergency Department Data Collection, Australian Bureau of Statistics Death Registry and Registry of Births, Deaths and Marriages. Mental health service utilisation among those with intellectual disability will be compared to a cohort of people who used mental health services (n=1,073,139) and service utilisation other than for mental health will be compared with published data from the general population.

Findings to Date: The median age of the cohort was 24 at the time of the last hospital admission and 21 at the last ED presentation. The cohort has a higher proportion of males than females and accounts for 0.6% of the NSW population in 2011. Over 70% had up to five ED presentations and hospitalisations between 2005-2012. A high proportion of people with intellectual disability live in the most disadvantaged neighbourhoods.

Future Plans: Results will be used to inform the development of more responsive healthcare, including improved interactions between health, social and disability supports. More generally, the results will assist the development of more inclusive policy frameworks for people with intellectual disability.

Keywords: *data linkage, mental health, service utilisation, intellectual disability, disability services, health services*

Strengths and Limitations

- This data linkage study builds a rich resource which allows the in depth examination of the health profile and service contact of people with intellectual disability.
- In the Australian context of dispersed and relatively low population size, this is the most efficient methodology, yet in itself requires considerable time and financial resources.
- Results will be used to inform the development of more appropriate service models and policy frameworks for people with intellectual disability.
- Our study includes only people with intellectual disability who have received disability services for intellectual disability or who have been diagnosed or identified by the hospital or emergency department as having an intellectual disability. It does not contain primary health care records.
- Administrative data are not collected specifically for research but rather for record keeping and aggregate data purposes; therefore, some variables of potential interest are not available.

INTRODUCTION

People with intellectual disability are a minority group, accounting for approximately 1% of the population[1]. Also known as Intellectual Developmental Disorder, intellectual disability, is an enduring condition involving impairment of general mental abilities which is first apparent during the developmental period and impacts significantly on the person's adaptive functioning[2]. Typically, a person with intellectual disability has an extremely low IQ score (measured as two or more standard deviations below the population mean) with deficits in adaptive behaviours and a reduced capacity to engage in conceptual cognitive functions such as learning, reasoning and planning[2]. Compared to the general population, people with intellectual disability are more likely to experience poor physical and mental health including complex health conditions such as epilepsy, sensory impairments, gastro-intestinal problems, respiratory disorders, obesity, diabetes, osteoporosis and oral health problems[3]. A lower life expectancy than the general population underscores the significant health inequality experienced by this population group[4].

The prevalence of mental disorders is very high, with recent estimates in children and adolescents with intellectual disabilities indicating comorbidity rates of between 30 and 50%[5]. Compared to the general population, people with intellectual disability experience higher rates of schizophrenia, affective disorders, anxiety disorders and dementia, and rates of mental disorders in this population increase in keeping with the degree of disability[6-8]. Schizophrenia has an earlier onset in people with intellectual disability, underscoring a specific developmental vulnerability to mental illness, and the importance of timely access to psychiatric services for this group[9].

Despite the over-representation of physical and mental disorders, access to health and mental health services for people with intellectual disability in Australia is limited and falls far short

of that for the general population[10, 11]. Barriers to effective health and mental health care for people with intellectual disability include: a lack of substantial epidemiological data on prevalence of physical and mental illness in people with intellectual disability; poor identification of people with intellectual disability due to masking and comorbidity[9]; unavailability or lack of appropriate application of existing assessment instruments; discrimination in healthcare systems[12]; a dearth of data on the interaction between, and distinct roles and responsibilities of, disability and mental health services[13]; a lack of training and confidence of health professionals in treating people with intellectual disability[14-17]; poor understanding by carers[18], disability and mental health workers of the manifestations of mental disorders in people with an intellectual disability[19, 20]; a lack of coherent service models; inadequate funding for intellectual disability mental health services[13]; poor coordination between services and treating agencies[21]; scant services preventing involvement in the criminal justice system[22] and a lack of specific inclusion of people with intellectual disability in the formulation of health and mental health policy.

Here we describe the creation of a linked administrative dataset resource from which we explore the health and mental health profile and service use of people with intellectual disability. Potential analyses include descriptive profiling of the diagnoses given to people with intellectual disability within health service systems, characteristics and predictors of service use and costs and examination of health outcomes and their predictors. Comparisons can be made with the general population, as derived from both the linked dataset and publically available statistics. Although the main objective of the overall program of work is to build a detailed profile of the health and health service system use of people with intellectual disability, the substantial unmet mental health needs of people with intellectual disability[13, 23] and award of specific funding have created an imperative for a specific mental health subtheme.

The data linkage which forms the basis for this work has been made possible through a National Health and Medical Research Council Australia funded Partnerships for Better Health grant (ID: APP1056128; Title: Improving the Mental Health Outcomes of People with an Intellectual Disability), which is a larger collaborative project including academics, government and non-government organisations and people with intellectual disability. The broader Partnership work has several themes including big data, qualitative work examining barriers and enablers to access, and a national and state policy analysis. A cohesive knowledge translation framework has been developed which triangulates results from each theme and uses the findings to guide the development of healthcare services and policy for people with intellectual disability and mental illness at both an Australian Government and State Government level. The data linkage component has several benefits including large sample sizes and the potential for greater efficiency in time and resources of longitudinal data. Interrogation of linked data identifies the linkages and gaps between service sectors, and the benefit of cross-sector work.

COHORT DESCRIPTION

Administrative datasets relating to disability services, health services and mortality in NSW, Australia, have been linked at an individual level to allow an examination of the pattern and determinants of service use/contact over time both for those with established intellectual disability and those without known intellectual disability.

Project Resourcing and Development

Considerable time and resources have been required to develop the data linkage component of the study. Piloting of the project occurred in 2012, when the team sought approval to link a

subset of one-third of the NSW ambulatory mental health dataset to the Disability Services Minimum Dataset (DS-MDS). Following proof of concept and publication of initial results[24] further funding was obtained to undertake the current linkage. Overall resourcing to date has been substantial and includes approximately 2 years full-time salary equivalents for a research officer, 2 year full-time salary equivalent for a data analyst, oversight of the project by a senior academic, substantial costs associated with linkage and storage of datasets, and multiple in kind contributions from partner agencies and collaborators.

Overview of data sources

There is no single registry which collects information about people with intellectual disability. In this project, multiple datasets have been utilised to help identify those with intellectual disability. All people identified as having intellectual disability fulfilled either Diagnostic and Statistical Manual of Mental Disorders (DSM) IV or International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10) criteria for a diagnosis of intellectual disability.

Disability services data

The Disability Services Minimum Dataset (DS-MDS) is a de-identified dataset which collates information about people receiving disability services in NSW, including the nature of their disability and the services provided to persons with a disability. The main services provided by the agency, Ageing, Disability and Home Care (ADHC), include accommodation, community support, community access and respite. Such information is routinely collected by each Australian State and Territory under the National Disability Agreement[25]. Given the services provided, the DS-MDS contains information on service recipients' demographics, living arrangements, support needs, carers and services received. A full list of the variables in this dataset is presented in Supplementary file 1. The DS-MDS includes n =

73,674 children and adults who resided in NSW and who were registered to receive a disability service between 01 July 2005 and 30 June 2012. From this dataset, a total of 42,243 people with intellectual disability was identified. Fulfilment of DSM IV criteria for intellectual disability was required in order to be eligible to receive a service due to intellectual disability.

Health Services Data

1. NSW Admitted Patient Data Collection

The NSW Admitted Patient Data Collection (APDC) is a de-identified dataset which collates information on all admitted patient services provided by NSW public hospitals, public psychiatric hospitals, public multi-purpose services, private hospitals, and private day procedures centres. It contains dates of admissions and separations for each episode of care, up to 50 diagnoses relevant to each episode of care, the source of referral, separation mode and procedures based on ICD-10 Australian version[26]. The current project includes APDC data on separations that occurred between 1 January 2005 and 30 June 2012 for 1,016,446 people. A list of the variables in this dataset is included in Supplementary file 2.

2. NSW Emergency Department Data Collection

The NSW Emergency Department Data Collection (EDDC) is a de-identified dataset which collates information on presentations to an emergency department in a NSW public hospital. It includes dates and times of presentation and discharge, reason for presentation, triage category and outcome of the presentation (discharge, transfer or death). The study includes data from 1 January 2005 to 30 June 2012 for 188,359 people. There are 150 ED centres in NSW and 90 (60%) of those participated in the data collection[27]. Although only 60% of the ED centres participated in the data collection, these reporting centres are the larger centres

hence a substantial proportion of the presenting population is covered. A listing of variables in the EDDC is displayed in Supplementary file 3.

Mortality Data

There are two datasets containing mortality information. Observations in both datasets are based on year of the registration of the death rather than the year the death occurred, although in most cases these are equivalent. The mortality information available for linkage includes only people who died in NSW.

1. NSW Registry of Births, Deaths and Marriages Data

The NSW Registry of Births, Deaths and Marriages (RBDM) registers all deaths that occur in NSW and contains death certificate raw and uncoded data. Data is available from January 2005 to June 2013. A listing of variables in the RBDM is displayed in Supplementary file 4.

2. Australian Bureau of Statistics Deaths Registration Data

The Australian Bureau of Statistics (ABS) Deaths Registration Data contains ICD-10 international version coded causes of death information and date of death. For our project, ICD-10 coded causes of deaths were available until 2007. A list of variables is included in Supplementary file 4. Data are available from January 2005 to December 2007.

Cohort definition

Our data linkage contains the records of a cohort of people with intellectual disability who have ever received disability services in NSW recorded in the DS-MDS described above (n = 73,674) and those who have been identified as having intellectual disability through diagnosis codes in the APDC and the EDDC in a NSW hospital. These “intellectual disability” codes are: F700-F701; F708-F709; F710-F711; F718-F719; F720-F721; F728-F729; F730-F731;

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3 F728-F729; F730- F731; F738-F739; F780-F781; F788-F791; F843-F844; F798-F799;
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5 Q900-Q902; Q909; Q910-Q912; Q913; Q914-Q916; Q917; Q930-Q939; Q992; P043; Q860;
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7 Q861; Q862; Q868 Q870-Q873; Q875; Q878; Q898. These codes include intellectual
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9 disability due to childhood disintegrative and overactive disorders associated with mental
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11 retardation, intellectual development delay, mild through profound mental retardation, Down
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13 syndrome and other chromosomal anomalies associated with mental retardation, Fragile X
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15 syndrome and congenital malformation syndromes due to known exogenous causes. Those
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17 diagnosed with autism without a co-occurring intellectual disability are not defined as having
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19 an intellectual disability for the purposes of this project. The intellectual disability cohort
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21 accounts for 0.6% of the NSW population in 2011 and people with mild intellectual disability
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23 may be underrepresented.
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28 To compare mental health profile and service utilisation in people with and without
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30 intellectual disability, a cohort comprising people who either used mental health services or
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32 who had a mental health diagnosis, regardless of the intellectual disability status, was also
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34 formed (n=1,073,139). People in this cohort had at least one admission to a psychiatric ward
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36 or were diagnosed with at least one mental health ICD10 code (F00-F25, F28-F48, F50, F51,
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38 F53-F73, F78-F91, F93-F99) during any hospital admission (psychiatric or non-psychiatric)
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40 or during any presentation to an emergency department. We then link this data to the
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42 intellectual disability status in order to quantify and compare rates and patterns of mental ill
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44 health in people with intellectual disability and the general population.
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49 For other health utilisation, we will compare the results of our cohort with information
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51 published by HealthStats NSW or the Australian Institute for Health and Welfare (AIHW).
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53 We will calculate rates of ED presentations, non-mental health hospital episodes and death in
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55 our cohort using appropriate datasets. For comparison with the general population, we will
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57 use AIHW published results for ED presentations in NSW and all cause hospitalisations in
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NSW as well as death from HealthStats NSW. To make direct comparisons between the cohort of people with intellectual disability and the general population, we will standardise the utilisation rates on age and sex using the Australian Standard Population. If published data permits, we will adjust for the impact of deprivation using the regression method.

Data Linkage

Linkage of the aforementioned datasets was performed by the NSW Centre for Health Record Linkage (CHeReL). The CHeReL maintains a linkage system for health-related data in NSW in accordance with all ethical, legal privacy and confidentiality requirements. The CHeReL keeps a Master Linkage Key (MLK) that consists of continuously updated links between most NSW Health datasets. The CheReL does not house the data; all datasets are kept by the respective data custodians.

Individuals in the DS-MDS were identified and their records matched in a deterministic manner using a Statistical Linkage Key (SLK581) identifier. Records in the APDC, EDDC, and RBDM are matched to individuals using an MLK[28]. The CHeReL created an SLK581 identifier for the matched APDC, EDDC, and RBDM records and linked this with the SLK581 keys in the DS-MDS. We do not have information on the false positive rate using the deterministic approach; however it is expected to be higher than 5/1000 aimed for by the CHeReL. Currently, the CHeReL linked 43,772 (59%) records of people in DS-MDS to APDC, EDDC, ABS or RBDM and 29,902 (41%) records did not link to APDC, EDDC, ABS or RBDM.

Data custodians provided the CHeReL with an encrypted client number and relevant personal information for all clients over the relevant time periods. The CHeReL linked the DS-MDS database to the NSW data collections of APDC, EDDC, ABS and RBDM using the linkage method described above, and provided each data custodian a project person number (PPN)

and an encrypted client number for each database. The data custodians decrypted the source record number and merged the PPN with their datasets for use in this project. The source record number was removed and the researchers were provided with de-identified files containing only the PPN and relevant study variables. The PPN allowed for merging the various datasets as needed.

Data cleaning and plan of analyses

Once the linked data was received, a data cleaning process was carried out including checking for unexpected trends, checking that the data was complete with all requested variables available and a validity check. People who appeared with a different sex or different data of birth/date of death in different datasets were excluded from the dataset.

The analyses described in this paper include the demographic profiles including age, sex, area of residence and socioeconomic status as well as health resource utilisation for people with intellectual disability.

Ethics

Ethics approval was obtained from the NSW Population and Health Services Research Ethics Committee (AU RED Study Reference Number: HREC/13/CIPHS/7; CINSW Reference Number: 2013/02/446) and access to the data sets was granted by relevant data custodians. An ethics requirement is that the linked data can only be analysed at the physical location of the researchers undertaking this work (The Department of Developmental Disability Neuropsychiatry, UNSW Sydney). The timeframe from submitting the ethics application to ethics approval was approximately 12 months and another 8 months from ethics approval to receipt of the data.

FINDINGS TO DATE

Figure 1 shows the number of people identified as having intellectual disability in the DS-MDS, APDC and EDDC datasets. Percentages of people with intellectual disability in each individual dataset are 82% (n = 42,243) in the DS-MDS; 47% (n = 24,242) in the EDDC and 55% (n = 28,233) in the APDC dataset. A total of 34% (n = 17,267) appear in all three datasets, 6% (n = 2,932) appear only in the DS-MDS and the APDC, 10% (n = 5,037) appear in both the DS-MDS and the EDDC and 4% (n = 1,898) appear in both the EDDC and the APDC. Note that in order to be included in our cohort, an individual had to receive a service with an intellectual disability flag. However, not all people with intellectual disability would necessarily also have a hospital admission or ED presentation record. Overall, 82% of the cohort received disability services due to their intellectual disability. Of the remaining 18% who did not receive disability services due to intellectual disability, 2.3% received disability services for non-intellectual disability related needs.

Figure 1

Table 1 displays the demographics of the study population in each dataset DS-MDS, APDC, EDDC and RBDM. The data shown is on a person level, and a person may have multiple records in the full analysis period of 2005 to 2012. Our cohort comprises 51,452 people with intellectual disability with a median age of 24 at the time of their last admission to a hospital or day procedure centre and a median age of 21 at their last presentation to an emergency department. The median age of death is 56 years. The cohort has a higher proportion of males than females: across the datasets, the proportions of males range between 57 and 60%. Two-

thirds of people live in a major city and about one-quarter lives in an inner regional city and 6% live in outer regional cities. Across all health services, only 15% of people with intellectual disability live in the least disadvantaged neighbourhoods.

Table 1: Health and intellectual disability service and mortality profiles as recorded in the dataset person level (at the last record), numbers presented in n (%) unless otherwise specified

	APDC	EDDC	Mortality (RBDM)	DS-MDS
Number of people (% of the defined cohort with intellectual disability)	28,233 (55)	24,242 (47)	2,844 (5.5)	42,243 (82)*
Median (IQR) age at the last event, years	24 (10 – 46)	21 (10 – 41)	56 (35 – 68)	23 (14 – 42)
0-4	3,408 (12.1)	2,115 (8.7)	160 (5.6)	1,022 (2.4)
5-14	5,878 (20.8)	6,197 (25.6)	149 (5.2)	10,258 (24.3)
15-24	4,955 (17.6)	5,202 (21.5)	194 (6.8)	10,987 (26.0)
25-34	3,279 (11.6)	3,048 (12.6)	181 (6.4)	5,842 (13.8)
35-44	3,210 (11.4)	2,618 (10.8)	246 (8.7)	4,832 (11.4)
45-54	2,993 (10.6)	2,361 (9.7)	424 (14.9)	4,511 (10.7)
55-64	2,466 (8.7)	1,768 (7.3)	556 (19.6)	3,237 (7.7)
65-74	1,306 (4.6)	688 (2.8)	494 (17.4)	1,203 (2.9)
75-84	580 (2.1)	203 (0.8)	323 (11.4)	284 (0.7)
85 and over	158 (0.6)	42 (0.2)	117 (4.1)	67 (0.2)
Sex				
Female	11,753 (41.6)	9,529 (39.3)	1,214 (42.7)	16,885 (40.0)
Male	16,480 (58.4)	14,712 (60.7)	1,629 (57.3)	25,334 (60.0)
Other	0	1 (0.0)	1 (0.0)	24 (0.1)
Ever received disability services	20,199 (71.5)	22,304 (92.0)	1,448 (50.9)	42,243 (100)
Remoteness Area of residence				
Major Cities	19,042 (67.5)	16,215 (66.9)	1,993 (70.1)	28,137 (66.6)
Inner regional	7,017 (24.9)	6,524 (26.9)	639 (22.5)	11,254 (26.6)
Outer regional	1,791 (6.3)	1,295 (5.3)	183 (6.4)	2,545 (6.0)
Remote	137 (0.5)	85 (0.4)	9 (0.3)	197 (0.5)
Very remote	7 (0.0)	8 (0.0)	1 (0.0)	9 (0.0)
Unknown	239 (0.9)	115 (0.5)	19 (0.7)	0 (0.0)
Index of Relative Socioeconomic Disadvantage in NSW of residence				
1 st quintile (most disadvantaged)	5,633 (20.0)	4,864 (20.1)	533 (18.7)	5,803 (13.7)
2 nd quintile	5,563 (19.7)	4,853 (20.0)	588 (20.7)	6,125 (14.5)
3 rd quintile	7,314 (25.9)	6,569 (27.1)	736 (25.9)	8,258 (19.6)
4 th quintile	5,523 (19.6)	4,655 (19.2)	560 (19.7)	5,902 (14.0)
5 th quintile (least disadvantaged)	3,965 (14.0)	3,190 (13.2)	408 (14.4)	4,439 (10.5)
Unknown	235 (0.8)	111 (0.5)	19 (0.7)	1,171 (2.7)

The demographics presented in the table are from the last admission or use of ED within the analysis period in each dataset.

Table 2 presents information from the APDC and EDDC datasets on a record level (i.e. multiple records for one person). As the RBDM is the same whether it is presented at a person (Table 1) or record level, it has not been retabulated in Table 2.

Proportions of intellectual disability are similar on a record level and on a person level basis. Percentages of the records in the APDC and in EDDC that were defined as from people with intellectual disability are 3% and 12%, respectively. Consistent across all datasets a higher proportion of males with intellectual disability receive health services than females (Tables 1 &2).

The proportion of people who received disability services is lower when assessed at the record level (59% and 78%) than on the person level (72% and 92%), in both the APDC and EDDC datasets. This indicates that those who have ever received disability services have, on average, fewer ED presentations and admissions to hospital than those who have not received disability services.

Overall, for the APDC and EDDC, there are on average 8 records per person in the full record database. The number of hospitalisations (data from the APDC) is displayed in Figure 2 and the number of ED presentations (data from the EDDC) is displayed in Figure 3. The distribution of the number of hospitalisations (APDC) and ED presentations (EDDC) is highly skewed.

Table 2: Health service profiles as recorded in the dataset (record level), numbers presented in n (%) unless otherwise specified

	APDC	EDDC
Total records	225,904	200,868
Date ranges	1 Jan 2005 – 30 Jun 2012	1 Jan 2005 – 30 Jun 2012

	APDC	EDDC
Median (IQR) age at the event, years	29 (11-49)	26 (13 – 42)
0-4	31,889 (14.1)	23,545 (11.7)
5-14	35,322 (15.6)	30,448 (15.2)
15-24	32,967 (14.6)	40,385 (20.1)
25-34	25,602 (11.3)	32,820 (16.3)
35-44	30,241 (13.4)	31,910 (15.9)
45-54	29,269 (13.0)	22,823 (11.4)
55-64	20,473 (9.1)	13,578 (6.8)
65-74	11,991 (5.3)	4,041 (2.0)
75-84	711 (3.2)	1,100 (0.6)
85 and over	1,038 (0.5)	213 (0.1)
Invalid data	1 (0.0)	5 (0.0)
Sex		
Female	100,387 (44.4)	87,930 (43.8)
Male	125,515 (55.6)	112,927 (56.2)
Other/missing	2 (0.0)	11 (0.0)
Ever received disability services	133,437 (59.1)	156,038 (77.7)
Remoteness Area of residence		
Major Cities	161,762 (71.9)	133,770 (66.6)
Inner regional	45,433 (21.1)	52,436 (26.1)
Outer regional	13,897 (5.8)	11,343 (5.7)
Remote	2,147 (0.6)	372 (0.2)
Very remote	61 (0.0)	38 (0.0)
Unknown	2,604 (0.7)	2,909 (1.5)
Index of Relative Socioeconomic Disadvantage in NSW of residence		
1 st quintile (most disadvantaged)	47,338 (21.0)	44,672 (22.2)
2 nd quintile	42,141 (18.7)	40,735 (20.3)
3 rd quintile	55,231 (24.5)	53,752 (26.8)
4 th quintile	45,153 (20.0)	38,005 (18.9)
5 th quintile (least disadvantaged)	33,455 (14.8)	20,818 (10.4)
Unknown	2,586 (1.4)	2,886 (1.4)

As seen in Figure 2 and 3, over 70% of people with intellectual disability have up to 5 ED presentations and hospitalisations.

Figure 2

Figure 3

Future Directions

Four major themes will be the focus of the project: hospital admissions, ED presentations, mortality and costs. Analyses will include predictors of hospital admission and re-admission,

frequency and length of stay for health and mental health admissions. We will investigate the demographics of people with intellectual disability who present at the Emergency Department, their rate of service use, arrival mode and whether ED presentations were considered a GP-type presentation. Mortality rates and predictors of mortality in people with intellectual disability will be examined as well as associations between use of disability services and comorbidities on mortality. Finally, costs of hospital services will be investigated.

STRENGTHS AND LIMITATIONS

Our linkage approach enables the inclusion of a broad range of people with intellectual disability in NSW, the most populous state in Australia. Similarities in demography between most states and territories in Australia enhances the generalisability of our results to Australian service users with an intellectual disability.

The data linkage enables us to conduct analyses examining patterns of service use related to different components of the health service system (inpatient, emergency, adult services, children and younger people’s services), and costs associated with health care, and mortality, cause and predictors of death. A greater understanding of service and indices of health system efficiency for people with intellectual disability will emerge, e.g. through the frequency and timeframe of readmissions to hospital, representations to ED and their predictors. The inclusion of an additional mental health cohort in our dataset will allow a direct comparison between the mental health profile and service use of people with and without intellectual disability.

The analysis of linked health and disability service data fills a current gap in the Australian knowledge base regarding the health profile and service system needs of intellectual disability. These data will be triangulated with the other two main projects within this

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3 program of research, to improve access to and quality of healthcare for people with
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5 intellectual disability.
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8 Our results will inform sector and services development. In light of the Australian rollout of
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10 the National Disability Insurance Scheme (NDIS) including in NSW, the project is an
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12 important source for informing policy and practices to improve the coordination between
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14 health and disability sectors. Our study will establish baseline health and mental health
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16 profiles, service use and costs across multiple components of the health services system,
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18 against which NDIS-related change can be interrogated.
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22 A number of challenges have been encountered in establishing this data infrastructure. The
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24 data linkage process is time- and resource -intensive. Researchers need to be aware that the
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26 process of applying for, combining and cleaning these dataset can take months or even years
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28 and requires experienced data analysts. In particular the relatively lengthy process of
29
30 applying for/waiting for the linked data and receiving ethics clearance can be a major
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32 challenge for research projects that are only funded from external sources for a limited
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34 amount of time. As with most administrative datasets, data has been collected for
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36 administrative rather than clinical purposes, and as such has significant shortcomings. For
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38 example, in the hospitalisation data, if a person had multiple diagnoses in one episode, we do
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40 not have information on the length of each diagnosis or the severity of it. Coverage is limited
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42 in three respects. Our data does not reflect all emergency department presentations because
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44 not all departments contribute to this minimum dataset. Importantly however, the majority of
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46 people live in areas with contributing emergency departments, so the impact is minimal in
47
48 our study. We cannot identify all people with intellectual disability, rather those who have
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50 received disability services for intellectual disability or who have been diagnosed or
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52 identified by the hospital or emergency department as having an intellectual disability.
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54 Therefore, we are missing those individuals with intellectual disability who were not
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considered eligible for disability services and in whom intellectual disability was not recognised or coded by health services. The excluded individuals are highly unlikely to be a random subset of those with intellectual disability; rather they are more likely to be people with milder intellectual disability and/or with additional disadvantage which limits access to services. Additional linkage to other datasets with intellectual disability identifiers would overcome this problem to some extent. Further, with the exception of the ability for direct comparison within mental health services, we do not have person level data of the general NSW population and hence need to compare other data-points to publically available data sources.

Record linkage can sometimes erroneously make false-positive links or fail to link when a true link exists (false negative). Additionally, administrative data are not collected specifically for research but rather for record keeping and aggregate data purposes. Some variables, for example, relating to severity of disability or measures of adaptive behaviour, that we would like to include in our models are not available in the data. In turn, this may increase the chances of omitted variable bias in our models. The current linkage does not include community health services or general practitioner records which may add additional value to the analyses as it requires linking data from different jurisdiction and not feasible at the time of this study. Finally, our cohort with intellectual disability is heterogeneous as we used multiple data sources with differences in definition or context of diagnosis of intellectual disability, which can be easily adjusted in the analyses.

An update of the cohort with inclusion of additional data is currently in progress. Specifically, we will add data from Corrective Services NSW, NSW Department of Education and NSW Public Guardian and we will extend the timeframe to 2001-2016. This will allow us to identify, quantify and cost health and other services provision to people with ID within the various cohorts of interest.

In conclusion by interrogating the linked disability and health datasets and triangulating this with data derived from an analysis of Commonwealth and State Mental Health Policy and a qualitative research approach with stakeholder engagement to improve accessibility, this project will inform the development of more appropriate service models and policy frameworks for people with intellectual disability.

COLLABORATION

Initial data analyses and publications will be generated by investigators on the NHMRC partnerships for better health: Improving the mental health outcomes for people with an intellectual disability. However, the research team is open to potential research collaborations; researchers interested in collaboration should contact the corresponding author with their expression of interest. Access to the data and analytical files is only permitted with the expressed permission of the approving human research ethics committees and data custodians. Analysis of linked data is currently authorised to occur at only one location, owing to ethical considerations.

Funding The study is part of a National Health and Medical Research Council Australia funded Partnerships for Better Health grant (ID: APP1056128; Title: Improving the Mental Health Outcomes of People with an Intellectual Disability).

Ethics approval Ethics approval was obtained from the NSW Population and Health Services Research Ethics Committee (AU RED Study Reference Number: HREC/13/CIPHS/7; CINSW Reference Number: 2013/02/446) and access to the data sets was granted by relevant data custodians.

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Project Staff and Students: Angela Dew, Preeyaporn Srasuebkul, Erin Whittle, Simone Reppermund, Snow Lee, Bronwyn Newman, Theresa Heintze

Partner Organisations: Agency for Clinical Innovation – Intellectual Disability Network, NSW Department of Family & Community Services - Ageing, Disability and Home Care, NSW Department of Education, NSW Department of Justice - Corrective Services NSW, NSW Ministry of Health – Justice Health & Forensic Mental Health Network, Mental Health Commission of NSW, NSW Ministry of Health – Mental Health & Drug & Alcohol Office, NSW Ministry of Health - InforMH, Mental Health Review Tribunal, National and NSW Council for Intellectual Disability, National Disability Services, NSW Office of the Public Guardian, NSW Ombudsman.

Data Sharing Direct access to the data and analytical files is not permitted without the expressed permission of the approving human research ethics committees and data custodians. Researchers interested in collaboration should contact the corresponding author with their expression of interest

Authors’ contributions JNT conceived and designed the study. KD, EE, DC, PS, EB, LD, TS, GS and TF participated in the conceptual design of the study. SR, PS, TH and JNT drafted the manuscript. PS and TH performed the analyses. TF provided statistical support. RR provided expertise about health economics. All authors critically revised the manuscript

and contributed to interpretation of the data. All authors read and approved the final version of the manuscript.

Competing Interests None

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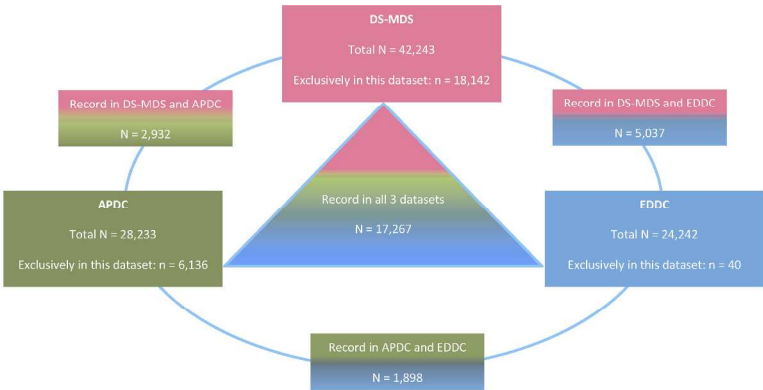
Figures

Figure 1: Number of people identified as having intellectual disability in the DS-MDS, APDC and EDDC datasets

Figure 2: Number of hospital admission for people with intellectual disability between January 2005 and June 2012

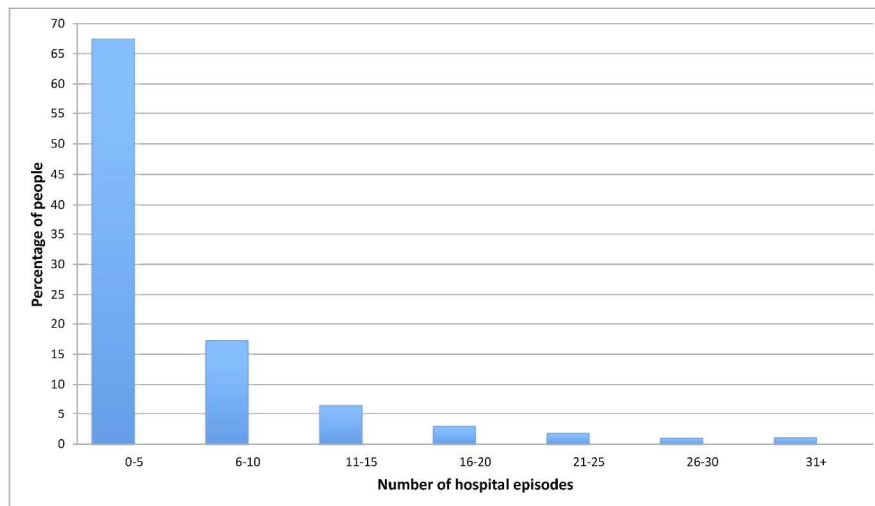
Figure 3: Number of emergency department presentations for people with intellectual disability between January 2005 and June 2012

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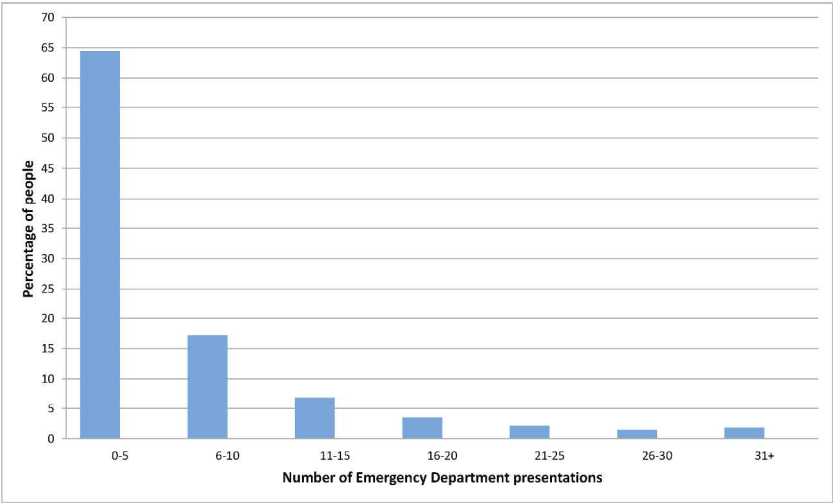


Note: the total cohort of people with intellectual disability is n= 51,452, comprising of n= 18,142 from the DS-MDS, 6,136 from the APDC, n= 40 from the EDDC, n= 2,932 with simultaneous records in the DS MDS & APDC, n= 5,037 with simultaneous records in the DS MDS and EDDC, n= 1,898 with simultaneous records in the APDC and EDDC and n= 17,267 with records in all 3 datasets.

Number of people identified as having intellectual disability in the DS-MDS, APDC and EDDC datasets
Figure 1
297x210mm (300 x 300 DPI)



Number of hospital admission for people with intellectual disability between January 2005 and June 2012
Figure 2
297x210mm (300 x 300 DPI)



Number of emergency department presentations for people with intellectual disability between January 2005 and June 2012

Figure 3
297x210mm (300 x 300 DPI)

Table 1: List of variables in Disability Service Minimum Data Set (DS-MDS)

Variable Name	Description
Service user	
Birth date	The day, month and year when the person was born.
Birth date estimate flag	Whether or not the person's date of birth has been estimated.
Sex	The gender of the person.
Indigenous status	Whether or not a person identifies themselves as being of Aboriginal and/or Torres Strait Islander origin.
Country of birth	The country in which the person was born.
Interpreter required	Requirement for interpreter services as perceived by the person seeking assistance.
Communication method	The method of communication, including sign language, most effectively used by the person.
Living arrangements	Whether the person lives alone or with other related or unrelated persons.
Residential setting	The type of physical accommodation in which the person usually resides ('usually' being 4 or more days per week on average).
Primary disability group	<p>One of: Intellectual, developmental disability, autism, acquired brain injury, Learning Disability, Neurological, or Psychiatric.</p> <p>Disability groups are a broad categorisation of disabilities in terms of the underlying health condition, impairment, activity limitations, participation restrictions and environmental factors.</p> <p>Primary disability group is the disability group that most clearly expresses the experience of disability by a person. The primary disability group can also be considered as the disability group causing the most difficulty to the person (overall difficulty in daily life, not just within the context of the support offered by this service).</p>
Secondary disability or other significant disability group	<p>One of: Intellectual, Development Disability, Autism, Acquired Brain Injury, Learning Disability, Neurological, Psychiatric</p> <p>Disability group(s) (other than that indicated as being 'primary') that also clearly express the experience of disability by a person and/or cause difficulty for the person.</p>
Support needs – self-care	The need for personal help or supervision in the area of: a. Self-care—activities such as washing oneself, dressing, eating and/or toileting.
Support needs – mobility	The need for personal help or supervision in the area of: b. Mobility—moving around the home and/or moving around away from home (for instance, using public

Variable Name	Description
	transport), getting in or out of bed or a chair.
Support needs – communication	The need for personal help or supervision in the area of: c. Communication—making self understood by strangers/family/friends/staff, in own native language or most effective method of communication if applicable, and understanding others.
Support needs – interpersonal interactions and relationships	The need for personal help or supervision in the area of: d. Interpersonal interactions and relationships—including, for example, actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions.
Support needs – learning applying knowledge and general tasks and demands	The need for personal help or supervision in the area of: e. Learning, applying knowledge and general tasks and demands—understanding new ideas, remembering, solving problems, making decisions, paying attention, undertaking single or multiple tasks, carrying out daily routines.
Support needs – education	The need for personal help or supervision in the area of: f. Education—for example, the actions, behaviours and tasks an individual needs to perform at school, college or any educational setting.
Support needs – community (civic) and economic life	The need for personal help or supervision in the area of: g. Community (civic) and economic life—for example, participating in recreation and leisure, religion and spirituality, human rights, political life and citizenship, and economic life such as handling money.
Support needs – domestic life	The need for personal help or supervision in the area of: h. Domestic life—undertaking activities such as shopping, organising meals, cleaning, disposing of garbage, housekeeping, cooking and home maintenance. (This does not include care of household members, animals and/or plants).
Support needs – working	The need for personal help or supervision in the area of: i. Working—for example, undertaking the actions, behaviours and tasks needed to obtain and retain paid employment.
Carer – existence of	Whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person requiring support.
Carer – residency status	Whether or not a carer lives with the person for whom they provide care and support.
Carer – primary status	Whether the carer assists the person requiring support, in one or more of the following activities of daily living: self-care, mobility or communication.
Carer – relationship to service user	The relationship of the carer to the person for whom they care.
Carer – age group of carer	The age group of the carer.
Receipt of Carer Allowance	Receipt of the Carer Allowance (Child) by a parent or

Variable Name	Description
(child)	guardian of a person, if the service user is aged less than 16 years.
Labour force status	The self-reported status the person currently has in being either in the labour force (employed/unemployed) or not in the labour force.
Main source of income	The main source of income of the person, if they are aged 16 years or more.
Individual funding status	Whether service user is currently receiving individualised funding under the National Disability Act (NDA).
Services Received	
Funded Agency ID	ID code generated for the funded disability service provider or agency.
Service Type Outlet ID	ID code generated for the agency's service type outlet.
Service start	The date on which a person began to receive support from a Disability-funded outlet.
Date service last received	The date the person last received a service of this service type during the reporting period.
Service exit date	The date on which the person ceases to be a service user of the NDA-funded outlet.
Main reason for cessation of service	The reason that the person stopped receiving services from the outlet.
Service quantity – hours received (reference week)	The number of hours of support received by a person for this NDA service type in the 7-day reference week preceding the end of the reporting period.
Service quantity - Hours received (total)	The total number of hours of support received by a person for this service type (summed over the reporting period).
Service quantity - Hours received (total) – specific service	The total number of hours of support received by a person for this NDA service type (summed over the reporting period).
Service Type Outlet	
Service type	The support activity that the outlet has been funded to provide under the NDA.
Service type outlet postcode	Postcode of the location of the outlet.
Funding jurisdiction	The jurisdiction (state, territory or Australian Government) providing NDA funding to the Service Provider and the jurisdiction in which the funds are allocated.
Agency sector	The type of government or non-government sector to which the Service Provider (or outlet) belongs.
Number of service users	Total number of people receiving a particular funded service type under the NDA during the reporting period.
Total CSDTA funds	Total amount (recorded in whole dollars) of Disability funds provided to the outlet for the current reporting period.
Other source of funds	The types of funding sources which apply to your agency.

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Table 2: List of variables in the APDC dataset

Variable
Hospital type (Public/Private)
Acute Hospital flag
Age
Area Health Service of facility
Local Health District of facility
Australian Refined Diagnosis Related Group
ARDRG version
Year and month
Clinical codeset
Condition onset flags
Cost weight A
Cost weight B
Cost weight C
Cost weight D
Cost weight E
Cost weight version
Country of birth (SACC)
Days in psychiatric unit
Diagnosis codes
DRG mode of separation
Emergency status
Emergency Department Status
Episode day stay length of stay in hours
Date
Episode end time
Episode leave days total
Episode length of stay
Episode of care type
Date
Episode start time
Facility type
Financial class
Financial program
Financial sub program
Health insurance on admit
Hours in ICU
Indigenous status
Involuntary days in psychiatric unit
Marital status
Major Diagnostic Category
Mode of separation
Patient postcode
Peer group
Procedure codes

Variable
Date
Recognised public hospital flag
Referred to on separation
Sex
Source of referral
Service Related Group
SRG version
State of residence
Unit type on admission
AHS 2005 CODE
LHD 2010 CODE
ML 2011 CODE
SA2 2011 CODE

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Table 3: List of variables in the EDDC dataset

Variable
Actual departure date
Actual departure time
Age
Arrival Date
Arrival time
Birth date
Clinical codeset
Country of birth
Departure ready time
Principal ED diagnosis
Referral source
Type of visit
Facility
Area Health service of Facility
Local Health District of Facility
Facility type
Doctor seen date
Doctor seen time
Nurse Practitioner seen date
Nurse Practitioner seen time
Indigenous status**
Marital status
Mode of arrival
Mode of separation
Need for interpreter Service
Postcode of residence
Peer group
Recognised public hospital flag
Referred to on departure
Sex
State of usual residence
Triage category
Triage date
Triage time
AHS 2005 CODE
LHD 2010 CODE
SA2 2011 CODE

Table 4: List of variables in the RBDM and ABS datasets

Variable
Date of birth
Date of death
Age at death in years
Year of death registration
Local Health District (LHD) Code 2010 (of residence)
SA4 Geographic Region 2011 Code (of residence)
SA3 Geographic Region 2011 Code (of residence)
SA2 Geographic Region 2011 Code (of residence)
Underlying cause of death
Contributing cause of death

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	comments
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	Title page
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Page 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 5-7
Objectives	3	State specific objectives, including any prespecified hypotheses	Page 6-7
Methods			
Study design	4	Present key elements of study design early in the paper	Page 7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 8-10
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Page 8-12
		(b) For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	A full list of all variables is listed in supplementary files 1-4. A summary of planned outcomes and future planned analyses is described on page 13-20
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 8-13
Bias	9	Describe any efforts to address potential sources of bias	Page 20
Study size	10	Explain how the study size was arrived at	Figure 1
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Only basic demographics are reported
		(b) Describe any methods used to examine subgroups and interactions	As above
		(c) Explain how missing data were addressed	As above
		(d) If applicable, explain how loss to follow-up was addressed	n/a
		(e) Describe any sensitivity analyses	n/a

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Table 1 and 2
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1 and 2. Page 13-17
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarise follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	n/a
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Key results will be reported in research paper. This is a cohort profile paper with limited results. Basic results and demographics are presented in Tables 1 and 2
		(b) Report category boundaries when continuous variables were categorized	n/a
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	18	Summarise key results with reference to study objectives	Key results will be reported in research paper. This is a cohort profile paper with limited results.
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 19-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Key results will be reported in research paper. This is a cohort profile paper with limited results.
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 20
Other information			
Funding	22	Give the source of funding and the role of the	Page 21

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fund-ers for the present study and, if
applicable, for the original study on which the
present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

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